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ABSTRACT

This special issue examines inclusive education, the movement to include children with disabilities in regular classrooms, focusing on the situation in New Jersey. The issue begins with an editorial by Ethan B. Ellis titled "Inclusive Education: Time To Pay Up." In "The Terms of the Debate," Marc Mercer notes that inclusive education means different things to different people, that the debate is deeply emotional, and that it hinges on the role of education as a social mission versus an academic mission. "Where Do the Educators Stand?" compares the positions of the New Jersey Department of Education and the New Jersey Education Association concerning inclusion. "Inclusion at Its Best" by Carrie Lerner offers photoessays of three students with disabilities who have been successfully included in regular education settings. "And at Its Worst" looks at factors that have led to some failures of inclusion, such as lack of planning, lack of collaboration, and funding mechanisms for special education. Other articles include: "Diana Cuthbertson: A Personal Story of Inclusion"; "Inclusion: An African-American Perspective"; "An Uneven Playing Field: Funding and Inclusion"; and "A Commentary on Inclusion: Us and Them." (JDD)

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THE NEW JERSEY DEVELOPMENTAL DISABILITIES COUNCIL

CN 700
32 West State Street
Trenton, NJ 08625-0700
(609) 292-3745
TDD (609) 777-3238
FAX (609) 292-7114

CHAIRWOMAN Colleen L. Fraser
VICE-CHAIRMAN Serge Sobolevitch, *Ph.D.*
Sidney Blanchard
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EXECUTIVE EDITOR Ethan B. Ellis
WRITER Marc Mercer
DESIGN AND PRODUCTION Virginia Persing, exceptional communications
PHOTOGRAPHY Simon Fulford

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Inclusive Education: Time to Pay Up

COMMENT

Ethan B. Ellis

"It's who you know, not what you know." True or not, this old cliche does point us in the direction of one important fact of life. Education is the principal gatekeeper in our society. It introduces us to knowledge and introduces us to other people and teaches us how to get to know them and get along with them. Either way, our success depends on it.

In New Jersey today, the vast majority of children with disabilities are getting a second-class introduction to life. Most of them—a higher percentage than in any other state—are being educated in segregated classrooms, many in segregated schools. The knowledge they are exposed to in these settings is artificially limited. So are the other people they are exposed to.

In this issue of PEOPLE WITH DISABILITIES, we look at inclusive education, the movement to include children with disabilities in regular classrooms with other children who don't have disabilities and teach them as much as they can learn with as much support as they need to be there and learn it.

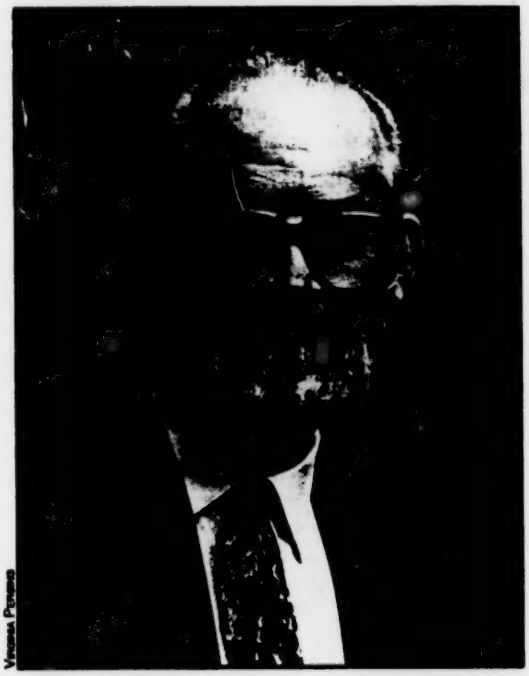
Inclusive education raises a lot of questions and has caused a fair amount of controversy. Is it good for all kids with disabilities? If not, who decides where the individual child is concerned? The parents? The teacher? The school? Are teachers prepared to teach all children with disabilities in the regular classroom? Do we know how to support them to do it well? Does the current method of funding public schools discourage inclusive education?

Some of these questions are complex and it's easy to get caught up in the debate about them and miss the main point.

The main point is that most of the kids we segregate today are needlessly segregated. The complexities of the debate over the inclusion of children with the most disabling conditions has distracted advocates, given school districts an excuse for inaction and left these kids stranded where they don't belong.

With proper supports, they could be in regular classes with other kids. They could be getting the same introduction to life, learning and people that we give other children as part of their birthright.

We owe them that and it's time we pay up. ❑



Vanessa Pompeo

"In New Jersey today, the vast majority of children with disabilities are getting a second-class introduction to life. Most of them—a higher percentage than in any other state—are being educated in segregated classrooms, many in segregated schools."

Correction

In the December 1993 PEOPLE WITH DISABILITIES issue on "Politics and Disability," the assemblyman shown on page 4—with self-advocate Adele Murad and Amy Mansue from the Florio campaign—was identified incorrectly. He is Leonard Lance (R) of District 23.

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by Marc Mercer

The Terms of the Debate

One comes quickly to one conclusion in listening to the debate over inclusive education. It clearly means different things to different people.

Curiously, both opponents and supporters of inclusive education spend an inordinate amount of time talking about students with extremely severe disabilities. Opponents use students with extremely serious disabilities and behavior problems as examples of the dangers of inclusion. Supporters generally use the successful inclusion of students with severe disabilities as evidence that inclusion works.

In a recent interview, Diana Cuthbertson, executive director of SPAN, acknowledged that this strategy may have backfired. "The vast majority of classified children have learning disabilities," she said. "They simply do not present the kinds of problems we normally discuss when we talk about inclusion."

"We seem to end up talking about the extreme cases, the small number of people who present really serious difficulties in regular education classrooms."

"We seem to end up talking about the extreme cases, the small number of people who present really serious difficulties in regular education classrooms," she added. "In some ways this really does distort the picture, though you cannot minimize the problems sometimes encountered in including some children with relatively mild disabilities."

Cuthbertson also feels that the discussion of the most extreme cases is sometimes a part of a classical pattern of bias. "Some people undoubtedly use these extreme situations as a way of raising the level of fear about the whole population," she said.

The real differences in the positions are fairly subtle. Supporters of inclusive education say that the presumption ought to be in favor of inclusion, in designing a student's educational plan. Opponents tend to talk of inclusive education as one of several potential educational options, with the selected option to be determined by the student's Individualized Education Plan.

At a state level, a good deal of the talk centers on the effect of inclusion on other students. Those against inclusion want language in regulations stating that the interests of other students in the classroom must be considered. Supporters of inclusion tend to resist such a notion, suggesting that it violates federal regulations and is just an indirect way of resisting including any student, since it would be difficult to prove that the student's presence would not disrupt the class.

Some practitioners of inclusion see this debate as largely irrelevant, from a practical point of view. "I find it hard to believe," one teacher told me, "that you could ever have a situation where inclusion would be good for the student, but bad for the class. It just doesn't work that way. If, after we have tried everything we can think of, a student's presence in a class is clearly bad for the class, I guarantee you that that student is not benefiting from that situation either. I guess it is a distant, obscure, theoretical possibility that under some peculiar combination of circumstances, it could be otherwise, but why should we spend so much time and energy talking about it?"

Perhaps the oddest circumstance of this debate is that both sides seemingly misstate the position of the other side and address arguments that no one makes. I could not find a single person favoring immediate inclusion of all students as a matter of civil rights. Opponents of inclusion assured me that this was the position of those favoring it. Advocates for inclusion do not take an "all or nothing" approach. They want inclusion approached carefully, with the proper resources and supports.

By the same token, I could not find anyone who was completely against inclusion—though some expressed serious reservations about the policy. These reservations tended to focus on the ability of the system to implement such a policy, not on the idea of inclusion itself. Some suggested that some school systems would simply regard inclusion as an excuse to save money on special services and throw children into classrooms without support.

One educator, identified by others as an implacable foe of inclusion, spoke of the Johnson City school system in New York, a system widely touted for a full inclusion approach, in such glowing terms that I asked her if she would like to work there. She agreed that she would. Her point was that this system provided the proper support and discretion to teachers and school authorities to make the approach work. She was quick to point out that many school systems in New Jersey are closed, authoritarian structures that do not provide a good environment for this approach.

Karen Melzer of the University Affiliated Program, a noted spokesperson for inclusion, stressed the need to frame the debate in practical terms. "It is almost as if we have forgotten what education is for," she said. "We have to look at the outcomes of the current system of special education. Do students come out of that system and get jobs or go on to higher education? No, they don't. Segregated special education is good preparation for living in a group home and working in a sheltered workshop. If we expect children with disabilities to work and live in the community, there can be no question that inclusive education offers the best preparation for that kind of future."

"Why bother passing the ADA," Diana Cuthbertson said at the end of her interview, "if you do not intend to bring people with disabilities into community life? Young people with disabilities will not be ready to take advantage of what the ADA promises if they do not, in their school careers, learn to live and work with others. It is equally important for nondisabled students to learn to live and work with people with disabilities, if that is what we are going to expect them to do in the future."

"I find it hard to believe that you could ever have a situation where inclusion would be good for the student, but bad for the class. It just doesn't work that way."

Supporters of inclusion point out that New Jersey has a huge investment in segregated programs and suggest that some of the resistance to inclusion is motivated by the interests that this investment creates. They question educational funding formulas that pay to send a child to a segregated program, but not to include the child in a regular education classroom.

"New Jersey's way of funding special education made sense 20 years ago," one advocate told me. "Now it is just another structural barrier to inclusion."

The debate is deeply emotional, on both sides. Positions tend to be strongly held and passionately defended. One is reminded, somehow, of the debate over closing institutions. Inclusion conjures up a similar sort of energy.

In some ways, the debate is about what education is, in the most basic sense. Supporters of inclusive education talk about a social mission, about preparing people for a more inclusive society where people with disabilities will work and live with the rest of us. Opponents tend to stress a more traditional academic mission. Some explicitly reject the notion that schools can be expected to address broad social issues.

It might be best to give Diana Cuthbertson the last word on this. "It is a conflict of world views," she said. "We see the same things. Some of us see impassable barriers. Some of us see surmountable obstacles." ❑

Diana Cuthbertson: A Personal Story of Inclusion

Diana Cuthbertson, the executive director of SPAN, is both a professional and the parent of a child who, prior to her death two years ago, experienced inclusion.

"The reason we saw [inclusive education] the way we did was because of my husband, Hank. Hank is legally blind. He was raised with the expectation that he would be part of the regular community. He didn't have a lot of supports, but he was successful. He works as a systems analyst for a bank in New York City. That experience formed how we saw these issues."

"It is an issue that parents come to at different times," she told us. "I had a friend who had a son with severe brain damage. I remember having a conversation with her about my concerns about Kate's transition to adulthood, about all the issues of independence. At the time, she seemed upset by it and asked me why we were even talking about such things. She was upset because she saw more immediate issues."

"A year later, she told me that she finally understood," Cuthbertson added. "I don't know what experience she had that changed how she saw it."

"The reason we saw it the way we did," she said, "was because of my husband, Hank. Hank is legally blind. He was raised with the expectation that he would be part of the regular community. He didn't have a lot of supports, but he was successful. He works as a systems analyst for a bank in New York City. That experience formed how we saw these issues. We tended to make different assumptions about the life of a person with a disability because of Hank's disability. We were more likely to think in terms of inclusion.

"She was a very gentle little girl. She loved to laugh and to be with us," Cuthbertson remembered. "She loved music, swimming and going to the ocean. One of my nicest memories of her is taking her to the beach when she was about six. She always had difficulty walking on her own. She went down to the water and found that she could use it as a means of orienting herself. She walked up and down the edge of the water on her own. She was so happy about it."

Kate Cuthbertson was born with cancer of the eye. She had radiation treatments. They saved her life, but the treatments left her with a variety of disabilities. "They didn't know much about the effects of early exposure to radiation then," Cuthbertson said, "but what choice would there have been, anyway? She never grew and her speech didn't develop. She could express her wants, but she never spoke in a paragraph."

When it came time for Kate to go to school, Cuthbertson found herself in a bind. "They saw a little girl with really big challenges," she recalled. "It must have seemed

The school district agreed to try inclusion. Kate went into a carefully chosen school with a hand-picked teacher—and it worked. Kate learned how to read braille and was eventually able to change classes on her own.

that we were not really talking about the same child. I tended to think in terms of inclusion, but I couldn't find anyone to talk with about it."

Kate did go to segregated classes for the early part of her career. Eventually, she developed a behavior problem. Cuthbertson took her back for a cancer check-up—and eventually concluded that the problem was that she just did not want to be where she was.

The school district agreed to try inclusion. Kate went into a carefully chosen school with a hand-picked teacher—and it worked. Kate learned how to read braille and was eventually able to change classes on her own. "They told me that these were things she would never be able to do," Cuthbertson said. "It seemed like a miracle."

Kate made friends with the other children easily. In fact, so many children wanted to help her that the teacher instituted a system that allowed them to take turns being Kate's buddy for a week. The other children learned their names in braille and seemed to be enriched by having Kate in their lives.

"The principal told me later that he had rehearsed a speech to give to parents concerned about Kate's presence in the classroom," Cuthbertson said. "He never had to use it."

Kate had an aide, who ended up changing her role from helper to facilitator. The children provided much of the help Kate needed.

Kate died from an aneurysm in her brain, probably caused by her exposure to radiation. She was unable to finish the school year. Cuthbertson agonized about what the other children must feel. She wrote letters to each of them, so that Kate wouldn't just disappear from their lives.

"They saw a little girl with really big challenges. It must have seemed that we were not really talking about the same child. I tended to think in terms of inclusion, but I couldn't find anyone to talk with about it."

In Kate's memory, Cuthbertson and others have set up a "friendship corner" in the library, with materials celebrating diversity and friendship.

Cuthbertson is clearly moved by talking about her daughter. She feels very strongly that that final experience of inclusion added immeasurably to the quality of Kate's life. She also feels that working for inclusion "is a way to continue to work on issues important to me when she was alive, and in a way, a connection to her."

"She was a very gentle little girl. She loved to laugh and to be with us. She loved music, swimming and going to the ocean. One of my nicest memories of her is taking her to the beach when she was about six. . . . She walked up and down the edge of the water on her own. She was so happy about it."

"Her death helped me focus on inclusion as a focus for my life," she concluded. ❑

Where Do the Educators Stand?

There is a lot of similarity in statements about inclusive education from the Department of Education and the powerful teachers' union, the New Jersey Education Association. Spokespeople for both organizations give the impression of people making their way through a minefield. Representatives of both agencies were very concerned about the potential mischief that might be made by a journalist unfamiliar with the issues.

They chose their words with care, conscious that every statement would be examined minutely by both sides of an extremely emotional debate.

And, with some slight differences in emphasis, their postitions are fairly close. Both see benefits in inclusion. Neither makes a commitment to a broad inclusion policy. The relevant policies in the Department of Education do not even contain the words "inclusive education."

Both leave the question of the inclusion of an individual student in the hands of local child study teams as a part of the process of developing the federally mandated Individualized Education Plan. A report of the Exceptional Children Committee of the NJEA puts it this way:

"Decisions about the appropriate education for an exceptional child must be individually determined and made with the active involvement of the varied professionals, including teachers and medical professionals, who have knowledge of the child and the educational environment in which the child might be placed."

This report, written for the NJEA Delegate Assembly in March 1992, predicates support for a policy of inclusion on assurances that there will be a funding mechanism for inclusion. The report also states concerns about the involvement of teachers in making decisions, the presence of medically fragile students in classrooms and the availability of proper support for the classroom teacher.

The report does not challenge the basic principles behind inclusion. The real differences may be in the tone. In private discussions educators emphasized that the problem is not with the idea of including students with disabilities—the real fear is that local school systems will implement an inclusion policy in a haphazard way, or will see inclusion as just a way to save money.

"If you look at the really successful examples of inclusion," one teacher told me, "you will see that the inclusion team was really empowered to make decisions and had strong support from administrators. You will find an emphasis on collaboration among the members of the team. This is not the atmosphere that many New Jersey teachers work within. Many administrators in this system are authoritarian and provide little power or support to the people doing the job. You can't separate inclusion from the kind of administrative reform that it takes to make it work."

There is, as well, a fear that a broad policy on inclusion might mean the elimination of all segregated programs. The NJEA report says: "[The committee] felt that the maintenance of a continuum of placements was vital to ensure that each child has the opportunity to receive an education consistent with his/her needs."

In the careful, diplomatic phrasing that characterizes this discussion, that constitutes a reaffirmation of support in segregated programs. Among educators, both supporters and opponents of inclusive education told me that part of the problem is with the history of special education in New Jersey. New Jersey was a pioneer in the area. In fact, New Jersey state law was one of the models used in developing the landmark federal law establishing special education on a national basis.

New Jersey developed a full range of segregated special education programs and was considered well ahead of other states for a number of years. With the shift in philosophy toward inclusion, states that had been slower to invest in segregated programs were able to establish inclusive programs more quickly. Many supporters of inclusive education feel

that the big institutional investment in segregated programs is a factor in the slow growth of inclusion in New Jersey.

The differences between the NJEA position and that of the Department of Education are subtle. Jeff Osowski, the official in charge of special education for the Department of Education, emphasized three points.

"One, there has to be a continuum of educational options," he told us. "Two, where the child is placed has to be based on individual planning—the program has to be designed to meet the kid's needs. And three, the child has to be in the least restrictive placement within the continuum appropriate to meet the child's educational needs."

Osowski says, with considerable justification, that inclusive education is a term that means different things to different people. He emphasizes the need to be precise about just what you mean by it.

Osowski points with pride to several successful inclusion programs around the state, but also observes that "studies suggest that New Jersey tends to be toward the bottom in the nation in terms of opportunities for children with disabilities to be in regular education classrooms, though the available data needs to be approached cautiously because of differences in the way New Jersey classifies children."

Osowski describes continuing efforts to develop training in inclusion, find approaches to collaborative teaching and establish a network of 18 districts with a commitment to inclusion programs.

He points at a variety of approaches to inclusion including both "pull-out" programs that take the child out of the regular class for special help and "resource room" teachers who provide support in class.

Osowski feels that some of the opposition to inclusion is "based on a misunderstanding of what we are trying to do." He does not foresee any wholesale movement of students with disabilities into regular education classrooms.

"I want to be in the business of providing the appropriate option for every child," he told us. "Granted, inclusion is hard to do, but the payoffs can be enormous for the child, for the other children and for the school."

"If you look at the really successful examples of inclusion, you will see that the inclusion team was really empowered to make decisions and had strong support from administrators. You will find an emphasis on collaboration among the members of the team."

And the tone is different. Osowski, though equally careful, obviously wants to market the potential benefits of inclusion, while assuring the many critics that the department will take a cautious approach.

Osowski comes in for considerable criticism from advocates for not taking a stronger stand in favor of inclusion, though many concede that he is in an unenviable position. He has to consider not only the position of the NJEA, but also that of the state board.

The state Board of Education has been embroiled in the inclusion debate. Over a period of several years, they have reviewed proposed regulations on inclusion several times. The regulations have never been finalized. According to an informed source, the issue of the potential negative impact of inclusion on other students has been a key issue in the debate. The state board has reportedly wanted to include a requirement in the regulations that the potential impact on classmates be a factor in considering inclusion for a student. Many advocates feel that such a requirement would violate federal regulations.

It is fair to say that the educational community is divided over inclusion issues. Though most educators favor inclusion for most students with disabilities, the question of a broad inclusion policy has still not been settled—and likely will not be settled for some time to come. ❑

Inclusion at Its Best . . .

Carrie Lerner

Photographs by Rebecca Shavulsky

It is difficult to tackle the question of inclusive education without talking to Amy Lerner. A great many of the people I interviewed asked, "Have you talked with Amy Lerner yet?"

We normally shy away from people who have been interviewed a lot. They tend to have pat answers, answers that insulate them from what they really think and feel. Still, I decided to interview Amy Lerner, and I am very glad I did.

Lerner is a busy woman, with two children and a small business she runs with her husband. I caught her just after a meeting on inclusive education at the University Affiliated Program. She was obviously dismayed to have guests, particularly guests with cameras, in the midst of the normal clutter of a busy home.

When Carrie came home, Lerner had to interrupt the interview to dress Carrie for Hebrew School. Like any other kid in the world, she wanted to watch television instead.

Lerner has made herself an expert on the subject of inclusive education. She did so because she felt that her daughter, Carrie, needed to be with other children.

"In the end, parents think about the fact that they will not always be here. What that tells me is that Carrie has to learn how to live in our society. Shielding her from the risk that is involved in being with other children would not serve her well."

"In the end, parents think about the fact that they will not always be here," Lerner told me. "What that tells me is that Carrie has to learn how to live in our society. Shielding her from the risk that is involved in being with other children would not serve her well."

"What are we going to do?" she continued. "Raise them in a vacuum until they are 21? Who is going to hire them? Who is going to work with them? Where are they going to live? If they are going to live and work with others in the community, they have to start learning how to deal with others now—and others, their future employers, coworkers and neighbors,

Carrie Lerner, who is mainstreamed in a regular classroom, spends 45 minutes a day in special education.

Above: Carrie and one of her friends

Below: Carrie and her friends on the school playground with Karen Shedlock, Carrie's special education teacher.

have to learn about them."

Lerner told a story that is familiar to anyone who talks a lot to parents of children with disabilities. "Carrie was born in great distress," she told me. "I knew almost immediately that something was not right, that she was not developing normally. The doctors told me that I was just comparing her to other children. Just another hysterical mother, I guess. They treated me as if I was the problem, but I just knew. Everyone else was into denial."

Lerner spent a tough 10 months before her feelings were finally confirmed. "It was actually a relief," she said. "I had been wondering what kind of terrible mother I must be to think as I did. Now I could deal with it."

Carrie Lerner has multiple neurological impairments. She does some things extremely well—and can't do others. She has mild cerebral palsy, communication difficulties and gross motor problems.

Carrie Lerner went to school in total segregation until she was 10. At that point, a gradual process of inclusion began. She has been in full inclusion for about a year. She has an aide with her in the classroom.

Amy Lerner clearly provided a lot of the force behind this process. "I think they may have gone along with me just to shut me up," she told me, "but, seriously, the school has been really wonderful."

"I always thought Carrie would be in a regular school," Lerner remarked. "I kept asking when she would be coming back into the mainstream. They kept saying 'Not yet.'

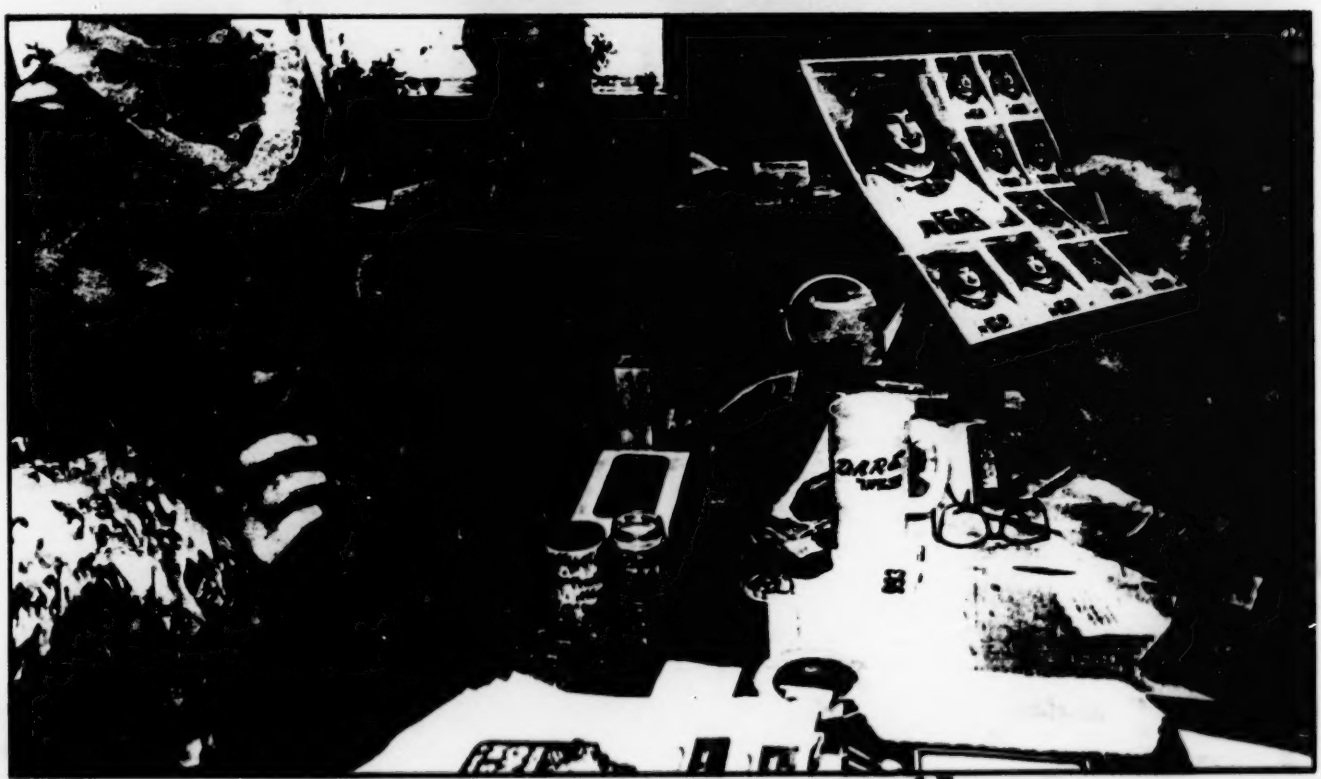
"She never had a single friend before . . . Now she has friends. She had a birthday party with 13 kids. I used to dread her birthdays. Now she even gets phone calls from friends from school. You can't engineer something like that."

Carrie plays with her friends at school; games that involve singing are Carrie's favorites.

"I always thought Carrie would be in a regular school. I kept asking when she would be coming back into the mainstream. They kept saying 'Not yet.' Not yet really meant never. There really was no clear definition of who would be included."

Right: Carrie works on the computer with special education teacher Karen Shedlock.

Below: Carrie and her friends receive their class pictures.

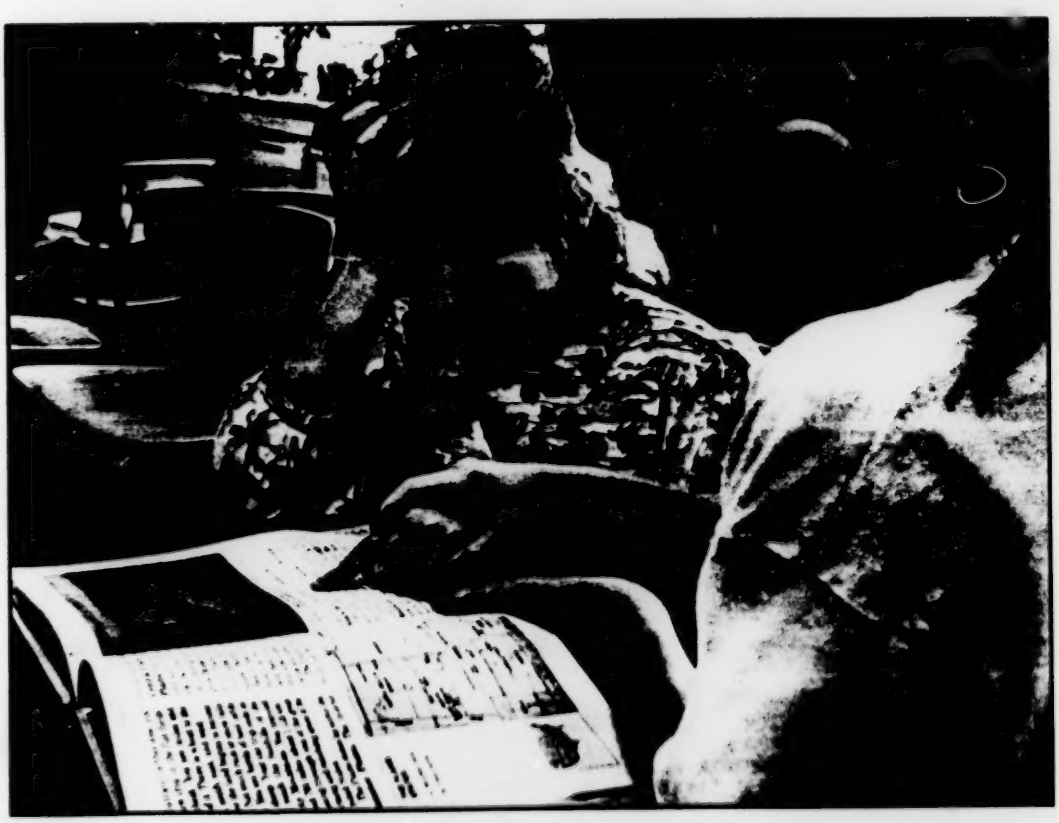


Not yet really meant never. There really was no clear definition of who would be included."

Inclusion has changed Carrie Lerner's life. "She never had a single friend before," Amy Lerner told us. "We would have kids over—you know, parent-engineered attempts to simulate real friends. Now she has friends. She had a birthday party with 13 kids. I used to dread her birthdays. Now she even gets phone calls from friends from school. You can't engineer something like that." There is a wistfulness in her voice. This is clearly something that has troubled her for a long time.

"And the academics, there's really no comparison with the segregated school," Lerner commented. "She spent years stacking rings in places where you had to learn how to stack rings before you were able to move on. She spent too long in schools that emphasized

"And the academics, there's really no comparison with the segregated school. [Carrie] spent years stacking rings in places where you had to learn how to stack rings before you were able to move on. She spent too long in schools that emphasized what she couldn't do. She could read before she was four years old. It took her forever to learn colors."



Many of the other children in school take responsibility for helping Carrie with reading and writing.

"It is when we don't define school so narrowly that we see the real value of [inclusive education]. School is not just math and science. It is preparing people for life."

what she couldn't do. She could read before she was four years old. It took her forever to learn colors. They didn't believe it was possible for someone to know how to read and not know her colors."

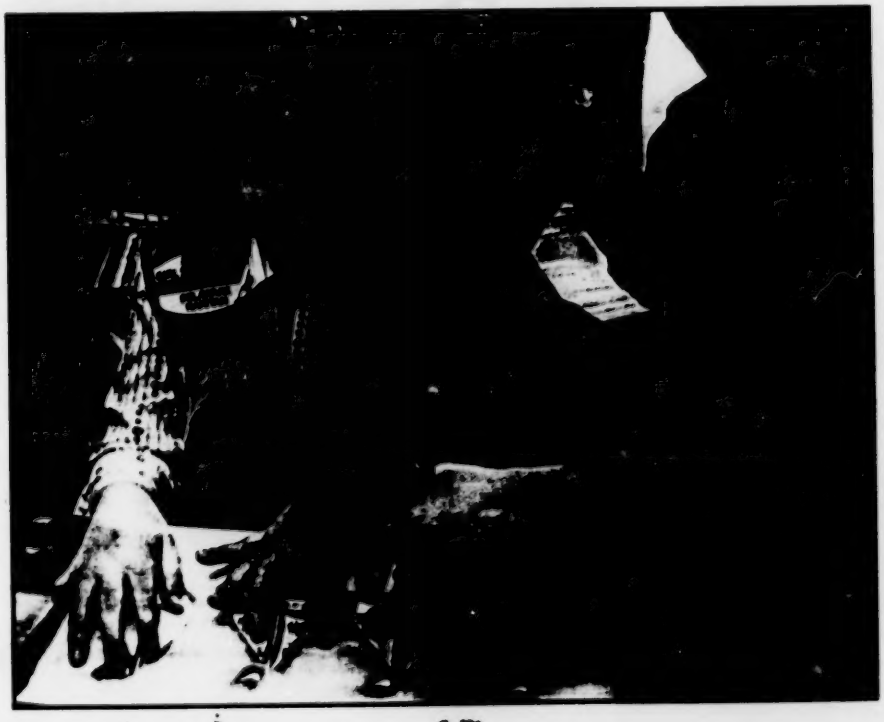
"She never played with toys, but she loved flash cards," Lerner added. "A lot of the teachers saw this as evidence that Mrs. Lerner doesn't accept her child's disability and pushes her into flash cards." There was a hint of bitterness in what she said. It is evident that some of the treatment Lerner received at the hands of professionals still rankles.

This is a common complaint of parents of children with disabilities. In the past skills like reading were often viewed by professionals as "splinter skills" and regarded as having no real meaning. In practice, this meant that the child's educational program ignored the child's strengths and interests and concentrated on tasks the child found difficult or boring.

Being included at school has generated inclusion in a lot of other places. Carrie is now in the Girl Scouts and attends Hebrew school. She seems to be genuinely well liked by other children at all of her activities—and accepted, despite her differences.

"There is something about human nature," Lerner remarked. "People are afraid of what they don't know and they do mean things out of fear. I think the learning experience for the other children is as important as what Carrie gets out of all of this."

A visit to Carrie's school in Hightstown would dispel even the most cynical doubts about the value of inclusion for this young girl and her classmates—and the team of educators



At a Girl Scout meeting, Carrie learns how to stencil.

Above and left: Carrie at Hebrew school

Being included at school has generated inclusion in a lot of other places. Carrie is now in the Girl Scouts and attends Hebrew school. She seems to be genuinely well liked by other children at all of her activities—and accepted, despite her differences.

"They think that it's funny that she can't do things. It makes me feel sad. She's just like us. If they ever really knew anyone like Carrie, they couldn't act that way."

Carrie with Adrianne and Tina, two of her best friends

working with her.

It may be that real learning is always on all sides—that everyone involved gets something out of any positive learning experience. Carrie's school program is certainly evidence of the truth of this proposition.

Don Radko, the school psychologist, acts as a facilitator for the instructional team. Donna Senesy, the classroom teacher, and Karen Shedlock, the special education teacher, work together in an atmosphere of mutual respect and open communication. All of the professionals regard Amy Lerner as a full member of the team. Perhaps, most importantly, they feel that they have the complete support of the principal and the administration of the school district.

"I would imagine that this could be a problem in some school districts," Donna Shedlock told us. "Commitment to inclusion has to start at the top. Our district has put a lot of time and effort behind this."

Senesy volunteered for the experiment. She identifies the ability to work collaboratively with another teacher in the classroom as the key to success. "I wouldn't say that this is for every teacher," she added. "It requires a degree of flexibility, a sense that there are different ways of being in control of the class. People who demand absolute, total control of everything at all times will probably not be comfortable with this. And there are teachers like that."

Radko sees the social teaching of Carrie's program as an important part of what is happening in the classroom. He sees evidence that the other students are learning lessons about diversity and tolerance that simply can't be taught with a book. "It is when we don't define school so narrowly that we see the real value of this," he said. "School is not just math and science. It is preparing people for life." We were standing in the hall outside the class. A small group of students, with Carrie among them, returned from the library. An African-American boy walks with Carrie, assisting her. They have found that Carrie walks better if someone walks with her, in

Carrie always has friends to walk her to class.

"Some of the children feel comfortable helping, and others don't. Sometimes the more troubled children are the ones who understand best."

"There is something about human nature. People are afraid of what they don't know and they do mean things out of fear. I think the learning experience for the other children is as important as what Carrie gets out of all of this."

close physical contact. "Some of the children feel comfortable helping, and others don't," Radko commented. "Sometimes the more troubled children are the ones who understand best."

Carrie wants to read when she returns to the class and is able to express this preference to the teacher. She really loves to read.

Watching the class for a while, it is clear that Carrie's presence does impact on the other children. They spend time helping her with her behavior. She sometimes bites herself or behaves in other ways that are inappropriate for the classroom. The children are part of a program to help her with these problems. They show her index cards that remind her not to bite herself. The team has found that Carrie responds well to the written word.

What are the benefits for the other children?

I had a brief talk with Adrianne, Carrie's best friend. She is a small, cute girl with big eyes—that grew bigger at the prospect of being interviewed by this huge person with gray hair and a beard. I ended up sitting on the floor to avoid towering over her. She seemed shy at first, but soon warmed up.

Adrianne recognizes that other children sometimes make fun of Carrie. "They think that it's funny that she can't do things," she said. "It makes me feel sad. She's just like us. If they ever really knew anyone like Carrie, they couldn't act that way."

Adrianne is not interested in being a teacher or a nurse. She has no particular vocation to help others, which, I must admit, I expected. She wants to be a fashion designer. She seems, in all respects, to be a very bright, very normal little girl who will grow up to be a productive citizen.

She will have one distinct advantage that many other children in New Jersey do not have. She has learned a valuable lesson about people. She knows that people are more the same than they are different. She has learned to view people who are different from her as people first. As I talked to her, she repeated all of these lessons in what she said.

Adrianne did not learn this valuable lesson from her teacher. She learned it from Carrie. ❑

She has learned a valuable lesson about people. She knows that people are more the same than they are different. She has learned to view people who are different from her as people first. . . . Adrianne did not learn this valuable lesson from her teacher. She learned it from Carrie.

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Photographs
by Simon Fulford

Michael Olivero

Stacy and Ron Olivero are teachers. If anyone could be expected to know how to make the school system work for a child with a disability, it would be them. They were already familiar with the weird alphabet soup of educational jargon. They knew about IEPs and child study teams. They knew the roles of the various professionals, and they could expect to be listened to with a greater degree of respect than the average parent.

Still, the path to an appropriate educational program for their son Michael, a child with autism, was not easy.

The Oliveros are a study in contrasts. Stacy Olivero is a very verbal, attractive woman with boundless energy. She is enthusiastic about inclusive education, and could talk about it for hours. Ron Olivero says very little. When he does speak, you expect him to speak softly, but he doesn't. He has a voice accustomed to cutting through the noise of a classroom full of children. It is soon evident that he is as involved, and as passionate about the issues of inclusion, as his wife.

Michael's disability was not diagnosed until he was over two years old. And even then the doctors did not use the word "autism."

"They called it a pervasive developmental disorder," Stacy Olivero told us. "He met all of his milestones as a baby, except for the development of language. He was a tough baby. When he wanted something, he would just keep crying until we figured out what it was. If they had told me 'autism,' I would have known where to go."

The goal for Michael, from the very beginning, was full inclusion. Today, after a long, gradual process, he has achieved that goal. He is in a full-time regular education classroom. And he is doing well academically.

Eventually, Stacy Olivero found her way to a parent support group run by COSAC (Center for Outreach and Services for the Autism Community, Inc.), the statewide advocacy organization for people with autism. It was there that she met Linda Meyer, one of the founders of the Alpine Learning Group. At that time, Meyer was acting as a facilitator for the group.

Olivero faithfully attended every meeting of the group, went to lectures, asked questions, read articles and generally sought to make herself an expert on the subject of autism.

Michael continued to develop in an eccentric pattern all his own, attending a special preschool program for children with developmental disabilities. His first word was "hamburger." Very early on, he somehow taught himself to read, though he would still not speak.

One day the looked at Stacy Olivero and said, "Hi Mommy."

"Right then I knew that this kid was mine and we were going to make it happen," Stacy Olivero told us.

The Oliveros began to have differences with some of the educators early on. The experts wanted to

Michael continued to develop in an eccentric pattern all his own, attending a special preschool program for children with developmental disabilities . . . Very early on, he somehow taught himself to read, though he would still not speak.

"[The trainers] have to make really close observations. He might be just tapping his pencil on his desk. With another child, you would ignore something like that. A child with autism might be totally lost in tapping the pencil and no longer attending to the teacher."

de-emphasize Michael's reading skills. The Oliveros wanted to build on them. They went around labeling everything in the house. They got him magnetic letters and encouraged him to spell things out.

In 1988, Michael was involved in a play group run by Linda Meyer and Bridget Taylor, another key player at Alpine Learning Group. The play group was, according to Olivero, "the model they used to build the school on."

The Oliveros had to fight hard to get Michael into Alpine, once it opened. "A lot of schools wanted him," Ron Olivero said. "He is high functioning and has good self-care skills. He would require a whole lot less help with a lot of things than most autistic kids."

The Oliveros kept pushing for Alpine, on the strength of their relationship with Meyer and Taylor. They felt strongly that it was the place for Michael. The school district wanted to send him to another program. Eventually, the Oliveros won.

The goal for Michael, from the very beginning, was full inclusion. Today, after a long, gradual process, he has achieved that goal. He is in a full-time regular education classroom. And he is doing well academically. He won a recent spelling bee. A trainer from Alpine sits in class with him, monitoring his progress and intervening when necessary.

"You have to be careful, though," his father told us. "Michael still does inappropriate things. He is really good at spelling, but that does not mean that he no longer has a disability."

Michael's teacher, Carol Hotz, is a very experienced classroom teacher who manages

Michael's teacher, Carol Hotz, is a very experienced classroom teacher who manages to involve Michael without seeming to make any special effort.

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"We have to get away from the fiction that all disabilities are alike. Placing children with physical disabilities in regular education classrooms is one thing. It may just be a matter of teachers and other students learning to tolerate diversity. Placing children with autism in regular school settings requires a whole different level of effort."

to involve Michael without seeming to make any special effort. The trainer, Susan Chatfield, watches Michael carefully, taking careful notes of his behavior. Occasionally, she prompts him about something.

"They have to make really close observations," Meyer explained in a recent interview. "He might be just tapping his pencil on his desk. With another child, you would ignore something like that. A child with autism might be totally lost in tapping the pencil and no longer attending to the teacher."

Michael's inclusion has spread too. He is involved in karate. He takes part in classes with no assistance. The teachers treat him just as they treat other students.

"This is the first really independent activity for Michael," Ron Olivero commented. "I sit with the other parents in the other room. I can't even see him from there, much less help him. And I think he wants it that way."

Michael is also deeply involved in private music lessons and is a promising pianist.

"He is really good at music," Stacy Olivero said, "but you need to understand that that does not mean that it always interests him. Like other kids, he has to be pushed to practice. Maybe he could play piano in a shopping mall one of these days," she adds. "That's a job."

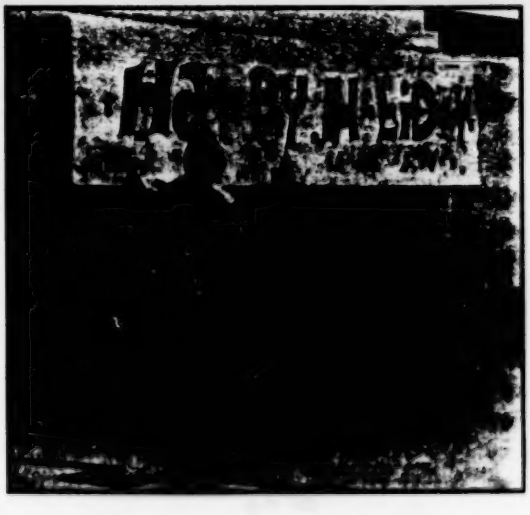
Susan Johnson, Linda Meyer and Bridget Taylor from the Alpine Learning Center discuss Michael.

Left: Michael works with his trainer from the Alpine Learning Center, Susan Chatfield.

Below: Susan Chatfield and and Bridget Taylor of the Alpine Learning Center observe Michael carefully.

Above: Michael with classmates working on computers

Right: Michael alone in the school gymnasium



Ron and Stacy Olivero have a great deal in common with many of the younger parents I have interviewed. They look to a future for Michael working and living in the community. Given that, they are anxious to see him gain experience in dealing with the nondisabled world. In their view, although a segregated environment was necessary in the early stages of his education, it is not the way to prepare Michael for survival in our society.

The Alpine Learning Group is a challenge to those who think that inclusion is a simple issue. Alpine is unquestionably a segregated environment, working only with children with autism.

They are pretty good at what they do. They always have a long list of families who would like to place a son or daughter in the program. They have mixed feelings about publicity. Past public exposure has resulted in calls from all over the country seeking admission. This may,

"We ask for a big commitment from parents, on the understanding that it is just not going to work otherwise. What we are teaching here has to be reinforced at home."

Top left: Michael's parents, Stacy and Ron Olivero

Left: Michael and his mother

Right: Michael and his big brother

Michael's inclusion has spread too. He is involved in karate. He takes part in classes with no assistance. The teachers treat him just as they treat other students.

as well, be an index of the desperation felt by many families of children with autism and the lack of resources for these children.

Alpine is one of those sacred places. It has a kind of quiet hush, like a library. It is difficult to describe the environment that Meyer, Taylor and their colleagues have created. It is serene, relaxed and accepting—though carefully planned and structured for each individual child. Alpine staff work with the children one to one. They also work with the families to maintain a seamless program for the child's entire waking life.

It quickly became clear that Meyer and Taylor are not selling any gimmicks. They are not really very interested in marketing a particular educational approach, although they follow the principles of "applied behavior analysis." "This program is empirically based," Taylor said bluntly.

What she meant is that they are open to a range of educational approaches. They stress the fundamentals. They monitor carefully and keep detailed records of progress. If an approach isn't working, they modify it, or try something else.

All of this may sound easy, but it isn't. It requires a highly motivated and well-trained team—and Alpine has built one. These people put in a full day of patient, sometimes frustrating work involving unrelenting concentration. It may appear very effortless, but building and maintaining a team like Alpine's is a masterpiece of administration requiring a high degree of commitment and skill.

The requirement to observe and record never slackens. As the children eat or interact "informally," Alpine staff keep their attention focused. They get a 15-minute break in the morning and one in the afternoon. They keep it up 11 months a year. They talk with seeming regret of the one month a year they need to "plan and regroup."

Four of the 21 children at Alpine spend part of their day in inclusion activities. Taylor made it clear that, while Alpine stresses inclusion whenever possible, that some of the children would probably be at Alpine for the duration of their school careers. Alpine runs a program involving play sessions between a nondisabled child and an Alpine student to teach some of the children normal social interactions—how to play with another child.

"The trouble is not that the children are not ready," Taylor said. "The system is not ready. Schools just do not provide the level of individual instruction and the careful monitoring required to work with many children with autism."

The demands of a home program for a child with autism can be intense. The Oliveros talked about "the summer we spent in the bathroom." For a period of time the family virtually moved into the smallest room in the house to reduce distractions and work with Michael intensively.

"The trouble is not that the children are not ready. The system is not ready. Schools just do not provide the level of individual instruction and the careful monitoring required to work with many children with autism."

Susan Johnson from Alpine works intensively with the parents in the development of home programs and in training parents to implement them. "We ask for a big commitment from parents," she told us, "on the understanding that it is just not going to work otherwise. What we are teaching here has to be reinforced at home."

All of this has paid off for Michael in a big way. He is a quiet, slight child with an air of vulnerability. During my interview with his parents, he played in the other room with his brother. They seemed to be having the kinds of disputes that brothers have. It would be easy, as Ron Olivero suggests, to forget that he has autism.

Some experts on autism maintain that this disability is, in some respects, a special case. They point out that children with autism need a carefully designed structured environment to learn.

"Schools do not provide that kind of environment," one expert on autism told us. "In that context, talking about including children with autism in regular education is scary. We support it when it is done right by places like Alpine. We are just concerned that it might be wholesale."

"We have to get away from the fiction that all disabilities are alike," he added. "Placing children with physical disabilities in regular education classrooms is one thing. It may just be a matter of teachers and other students learning to tolerate diversity. Placing children with autism in regular school settings requires a whole different level of effort. Unless and until we get a big change in the school system, we have to approach inclusion policies with caution." ❑

Left: Michael practices karate.

Below: Michael plays the piano for his music teacher.

Jonathan Jusino of
Jersey City

Getting Ready for Work in Hudson County

When people think of inclusion, they usually think of inclusive education, they usually think of children with disabilities coming into regular education classrooms. Dr. Alex De Noble, director of special services for Hudson County's vocational and technical schools has a couple of additional wrinkles.

For one thing, he is the "father of reverse inclusion." He has made extensive use of a strategy of creating inclusion by bringing regular education into facilities formerly dedicated to segregated programs. This strategy promises to provide a means of transitioning segregated programs into inclusion without losing the investment made in special programs.

De Noble and his crew are also including former special education students in a range of learning situations where they have never been seen before. They are learning a variety of vocational skills—sometimes on the job at real work sites in the public and private sectors.

"It isn't always easy," De Noble said. "You will find that a guy who teaches plumbing is often not real open to doing things in a different way. That's the way he learned it, and that's the way it has to be. He may not be comfortable modifying the way the job gets done for an individual student with a disability."

"Safety is a big issue," De Noble added, "we have people doing things in environments where a mistake can get someone hurt. We can't disregard that as an issue when it comes to putting a child with a disability—or any other child—in a situation like that."

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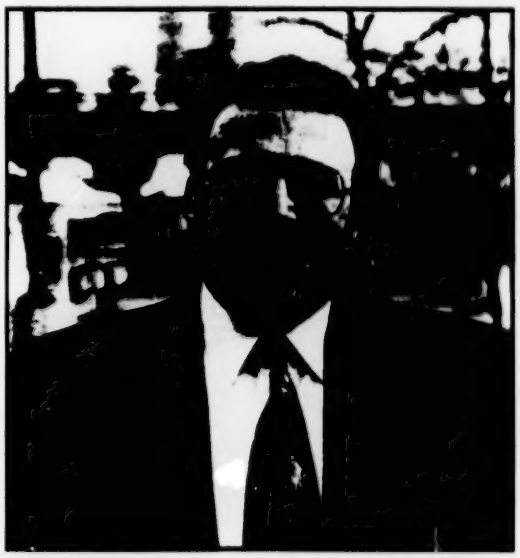


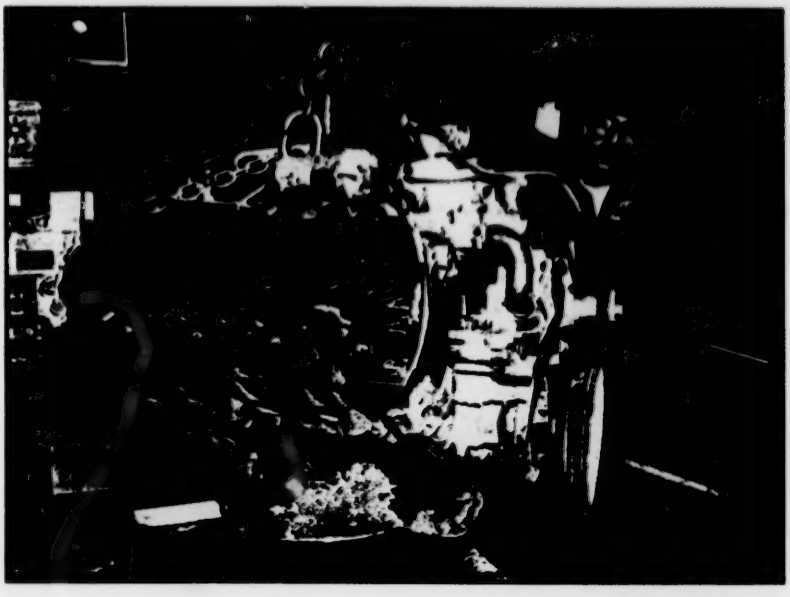
Alex De Noble, director of special services for Hudson County's vocational and technical schools

"It isn't always easy. You will find that a guy who teaches plumbing is often not real open to doing things in a different way . . . He may not be comfortable modifying the way the job gets done for an individual student with a disability."

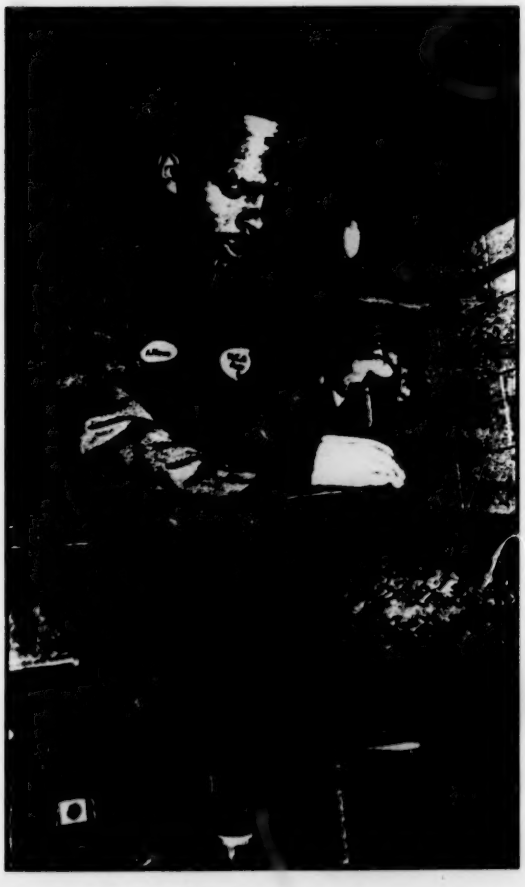
Henry O'Brien and
Philip Wilson at the
Jersey City
Incinerator
Authority

De Noble and his people take essentially the same approach that other successful inclusion programs take. They do a lot of planning and monitoring of individual programs for students. They work closely with the vocational and technical instructors to support the placements.

During our visit, De Noble did what good administrators often do to us. He used us as a way of recognizing the efforts of his staff and the instructors. This meant that we got marched into as many shops and classrooms as possible and were bombarded with a bewildering blizzard of information. One thing that emerged immediately is that the people around De Noble have enormous respect for him and that he maintains warm, open communications with everyone involved. More than that, his colleagues like him.



Ricardo Iturrelde

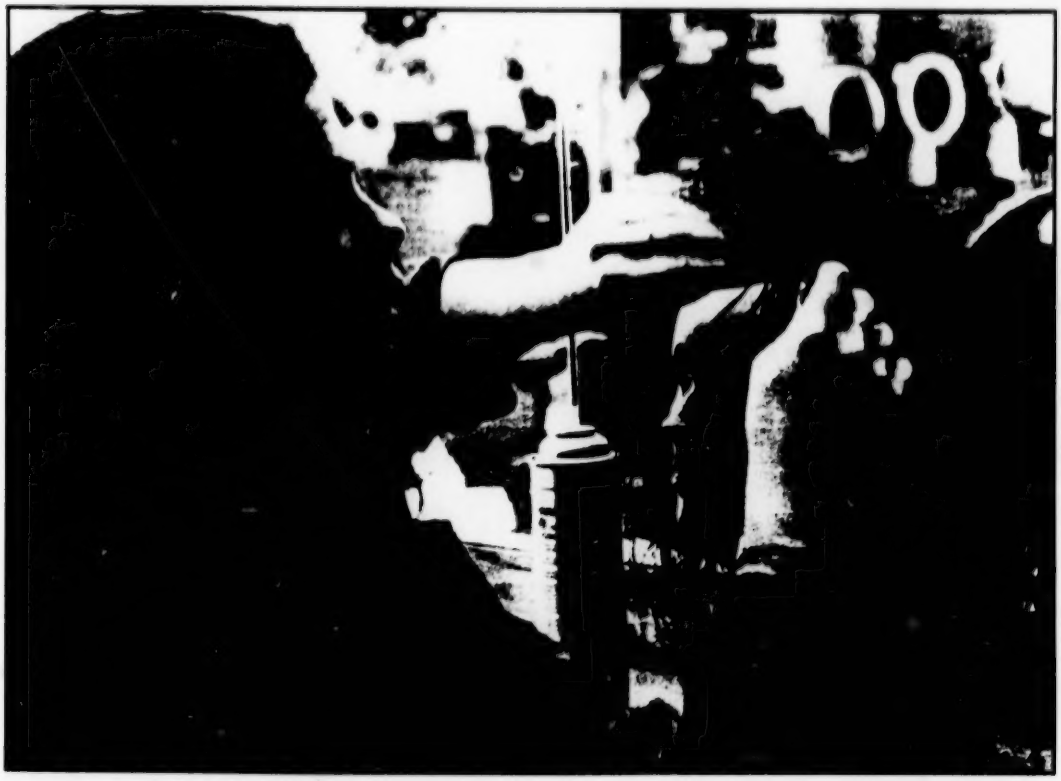


Amaury Nova

De Noble is a bit of a character—a fast-talking American urbanite with a touch of mischief. He talked me into beginning an interview with one of the teachers, a basketball-playing buddy, with the line, "Is it true that you have absolutely no shot?" He took us to lunch at a truly awful lunch counter in Bayonne where the aging owner kept a baseball bat in plain sight behind the counter to discourage unruly customers. De Noble picked up the check with a flourish and a breezy, "expense account."

De Noble and his people take essentially the same approach that other successful inclusion programs take. They do a lot of planning and monitoring of individual programs for students. They work closely with the vocational and technical instructors to support the placements.

Gavin Cummings, Cannis Coffe, Joseph Santomavro and Edwin Johnson of Jersey City



Nadiuska Negron of Bayonne vo-tech

One of the most frequent criticisms of special education is that it does not prepare people for competitive employment. There is no question that these special education students have been given realistic vocational preparation.

We visited with some special education students in Bayonne and Jersey city preparing for a variety of careers.

Susan Roesing is in a program that prepares medical professionals. Her ultimate goal is to become a registered nurse. For now, she is looking forward to another year of school before going into a two-year college program. Part of her day is spent at a local hospital.

Naidiuska Negron is in a cosmetology course. Negron has autism and an aide accompanies her to class, though she no longer requires much assistance. She is particularly good with manicures and plans to work in a salon after graduating.

Other special education students were involved in learning welding, auto mechanics, construction trades and landscaping. The landscaping students tend the grounds of their school in Jersey City.

Several students are part of a program that puts them onto actual work situations for part of the day. Alex Zieniuk works as a job coach at the school, identifying potential work sites for students.

Henry O'Brien works with welder Philip Wilson at the Jersey City Incinerator Authority. O'Brien has the opportunity to learn from an experienced welder on the job.

Niraj Sheth works in the stockroom of Ramp Auto Parts in Jersey City.

One of the most frequent criticisms of special education is that it does not prepare people for competitive employment. There is no question that these special education students have been given realistic vocational preparation. This is a program that will continue to pay off for years to come. ❑

Susan Roesing of Bayonne vo-tech

Jonathan Jusino and
Troy Boatwright

And at Its Worst . . .

We couldn't find anyone involved in an unsuccessful inclusion who was willing to talk for publication. Most said that their case was being litigated. In fairness, though, we need to point out that some parents have resisted attempts to include a child in regular education classes.

And some teachers report attempts at inclusion that they feel are unwise. One South Jersey shop teacher stated concerns about the physical safety of students with disabilities in his class. "You won't find many teachers willing to talk with you," he said, "but a lot of teachers are privately very concerned."

Edward Dragan, an educational consultant specializing in inclusion programs, gave us an overall perspective on inclusion policy. "You cannot usefully separate inclusion from other educational reform," he told us. "If you look at successful examples of inclusion, you will see several common features. You will see that there is high-level support of inclusion from the administration. You will see that there has been careful planning. You will see that there is an environment that supports collaboration between the professionals."

"If you look at the failures," he added, "you will find a lack of planning and a lack of collaboration. You will find that people have just put kids with disabilities in a classroom and called it inclusion. You will find that the background issues of turf have not been resolved. A whole lot of teachers have a problem having another teacher in the classroom with them. And many school systems are rigid, authoritarian and closed to new ideas. It is misleading to see these failures as failures of inclusion."

"If you look at the failures, you will find a lack of planning and a lack of collaboration. You will find that people have just put kids with disabilities in a classroom and called it inclusion. You will find that the background issues of turf have not been resolved."

Dragan favors a moderate approach to inclusion at a state level. He believes that the Department of Education should make a strong statement favoring, though not requiring inclusion—and a continuation and expansion of efforts to provide incentives for school systems to take an inclusive approach.

"The most important thing, immediately, would be to remove the structural barriers to inclusion created by the way special education is funded," he remarked. "The current system clearly favors segregation and too many school systems make decisions that are based on what brings in the money, not what's good for the kids." ❑

"You cannot usefully separate inclusion from other educational reform. If you look at successful examples of inclusion, you will see several common features. You will see that there is high-level support of inclusion from the administration. . . . You will see that there has been careful planning."

Inclusion: An African-American Perspective

Kabili Tayari is the education director for the NAACP. As such, he has a unique perspective on inclusive education.

Tayari, though not an educator, has been involved in educational advocacy since he was in college. He got interested when the child of a woman he knew was expelled from elementary school for saying "damn you" to a teacher.

"Most parents, white or African-American, give up a whole lot of power to the school system," he told us. "They develop a whole lot of caution and fear. They feel that if they criticize the school, if they don't just rubber stamp whatever program educators come up with, the child will pay."

"Most parents, white or African-American, give up a whole lot of power to the school system. They develop a whole lot of caution and fear. They feel that if they criticize the school, if they don't just rubber stamp whatever program educators come up with, the child will pay."

"When it comes to special ed," he added, "what educators say about parental involvement often just isn't true. Parents often have few rights—rights that they know about and know how to assert anyway. A lot of them have never seen an IEP. They are not informed of their rights at any point of the process. Most parents do not know that their child can go to a school out of the district. The Department of Education does not advertise this option."

"The result," he concluded, "is that the people who get the best service from the system are people who have resources, middle-class and upper-middle-class people who know how to make the system work for them. It isn't just a racial thing. Poor white people get left out too."

Tayari sees all forms of segregated education as overlapping. He feels strongly that African-American and Latino students are disproportionately represented in all of them. He views special education, bilingual education and so-called Chapter One programs as usually unacceptable alternatives to regular education. Chapter One programs are federally mandated remedial education for children who fall below certain norms on standardized tests.

"Jimmy Carter's daughter Amy was in Chapter One," he said. "She got remedial help and came out of the program. That is how it is supposed to work. That is not how it works for African-American and Latino children. Once they are out of the mainstream in any of these programs, they never seem to make it back. They are over-represented in all of these segregated programs. And this is not just an inner-city phenomenon. You can go into schools in Morris County and find the same thing. Our experience is that these children are placed in these segregated programs for the least little thing—the slightest behavior problem. And they never come out."

Tayari firmly believes that none of the segregated programs offer adequate services. "What you have here is tantamount to a decision that a certain class of children, a certain race of children, are not going to get a

"Once [African-American and Latino children] are out of the mainstream in any of these programs, they never seem to make it back. They are over-represented in all of these segregated programs."

quality education, are not going to be ready for the job market and are not going on to college."

"Kids with special needs often get some bullshit, watered-down curriculum, regardless of their abilities," he remarked. "I remember one child who was in a special program because he had one leg shorter than the other. He wanted to go to college and probably could have. They put him in a segregated program that took him out of the college track. Why?"

Tayari had at least a partial answer to his own question. "There is big money involved in special education," he remarked. "In most school districts there aren't enough professionals to make up child study teams of all of the classified kids. It's a moneymaker for consultants. There are some big salaries getting made."

Tayari sees the movement toward inclusive education as a partial solution to the problem of African-American and Latino children in segregated programs. "Our community can benefit a lot from this," he said, "though I need to stress that this is more an issue of class than race. Children from poor white families can benefit too. Still, I think you have to recognize that the people currently benefiting from inclusive education tend to be those same people who do better in the educational system generally. It may take a while for inclusive education to have much effect on the lives of poor children."

"People who get the best service from the system are people who have resources, middle-class and upper-middle-class people who know how to make the system work for them. It isn't just a racial thing. Poor white people get left out too."

Tayari is interested in measures to make schools more answerable to consumers. He favors the development of an ombudsman program in each school system to safeguard the rights of children and families.

Tayari supports other reform measures including outcome-based education. "As long as parents don't know what their children are supposed to be able to do at a particular grade level," he commented, "how can they hold the school accountable? If there was a mandated curriculum for all children, parents would know where their children should be at a given age."

"What you have here is tantamount to a decision that a certain class of children, a certain race of children, are not going to get a quality education, are not going to be ready for the job market and are not going on to college."

He feels strongly that the state Department of Education needs to do better monitoring of special education, including random interviews with parents to determine whether they were really involved in the development of the Individualized Educational Plan (IEP), as required by both state and federal regulations.

Tayari is not naive about educational politics. "This is a real big power base in poor communities," he remarked. "Education is a big budget with all of the opportunities for patronage and nepotism. It's easy to say that people should see the education of children as an issue that should be above politics. It's easy to say that." ❑

An Uneven Playing Field: Funding and Inclusion

In the past two years, funding for special education has increased by nearly 90%. According to a recent report compiled by the Arc, this brings total expenditures on these services to $612 million.

Nationally, states classify about 12% of students. New Jersey classifies 16%. Some districts classify as many as 31%.

The Arc of New Jersey and other education advocates conclude that the problem isn't money. They do not call for an increase in funding. They believe that reforms in the system could bring better services for no increase in cost.

Funding for education in New Jersey comes from a variety of sources. There are unbelievably complex formulas to determine how much state aid a district gets—and how much the local district has to pay. You will find hardly anyone willing to defend this system as rational or fair—and reforming it is currently a hot-button issue at the legislature.

Children in special education generate additional revenues, over and above the state aid produced by the funding formulas—though there are additional formulas to determine the amount of special education funding the district receives for a student.

The district is not, however, constrained to spend the money generated for special education on special education. If the program for the student costs less than the available funds, the district can make a profit on special education. It is estimated that about half of the state's districts make money in this manner.

Not spending the money a child generates on the child's program obviously defeats the whole intent of the funding program and creates incentives to have a lot of special education students and to serve them as cheaply as possible.

The Arc produces some evidence that this is no armchair conspiracy theory. Nationally, states classify about 12% of students. New Jersey classifies 16%. Some districts classify as many as 31% of all students.

When you consider the negative impacts of labeling, the classification of such large numbers of children has to be a concern.

As the Arc report points out, there is a public perception that the costs for special education are skyrocketing. There is, however, no guarantee that the increases in funding have actually paid for special education programming.

There are, additionally, incentives in the system to place children in segregated programs. These programs produce more funding. A child classified as "educable mentally retarded" generates $3,150 in a resource center program, $4,200 in a separate class or private school, and $9,660 in a special services school district. That is to say that the available funding increases with the level of segregation.

Advocates claim that placement decisions are often driven by money—and segregation pays. On the other hand, inclusion costs. Districts pay the tab if the child is "included" in a general education classroom—there is no state aid for any supports the district provides there.

Calls for reform of this system have been made by advocates and politicians. There will probably be legislation to level the playing field on inclusion in the next legislative session. Reform is long overdue. ❑

There are incentives in the system to place children in segregated programs.

As I wrote you on November 9th, we xeroxed copies of the June Issue of PEOPLE WITH DISABILITIES, when we found we could not obtain additional copies of that issue from your office. We distributed the copies to our Board of Directors and to our member groups.

Everyone who has seen the journal is very impressed and we hope you don't mind if we xerox additional copies for other groups that advocate for persons with disabilities. We are all working for a better quality of life for persons with disabilities; we feel, and hope you agree, that sharing useful information is an important component of this work.

Roy K. Jetter
President, FORConn
Friends of Retarded Citizens of Connecticut, Inc.

***Editor's note:** Reprints of two of our most popular "collector" issues—the June 1993 issue on institutions and the August 1993 issue on community services—will be available in March 1994. To request copies of these issues, free of charge, call or write the New Jersey Developmental Disabilities Council.*

PEOPLE WITH DISABILITIES Goes Electric

PEOPLE WITH DISABILITIES is now available as a file for download on DHS Online, the electronic bulletin board of the New Jersey Department of Human Services. We also have a feedback section and other features to allow our readers to get involved in discussing the issues we write about. To get to us, log on to DHS Online and select "News." Then select "PWD Mag."

These are some of the features and advantages of the electronic edition of PEOPLE WITH DISABILITIES:

- Picture descriptions will be provided for blind readers.
- Readers wishing to reprint articles or display the magazine in large print on a computer will find these files useful.
- Online readers will have a slight jump on those waiting for the mail delivery of the magazine.
- Readers will also be able to write letters to the editor in the feedback section. Private e-mail may be sent to "PWD Group" on DHS Online. Internet users can contact PEOPLE WITH DISABILITIES at cthw07a@prodigy.com. Your thoughts and suggestions are very welcome.

To log onto DHS Online, set your communications software to a VT100 terminal emulation. Set the parameters to any baud rate up to 14.4K, no parity, 1 stop bit and 8 data bits. These are the default parameters on most software. Dial into (609)292-4566. Follow the instructions on the screen from there.

You can get Windows or Mac software for DHS Online or technical help by calling (609) 633-6854.

You will find a good deal of useful information and discussion on DHS Online. This communications technology is the future of this and other fields.

Get involved now. ❑

PWD Online: Starting February 1

PEOPLE WITH DISABILITIES is sponsoring the first in a series on online discussions as one of the features of PEOPLE WITH DISABILITIES Online. The topic for the first debate, available at this time, is "Unresolved Issues." What are the major unresolved issues facing the disability community and the service system at this time? Guest experts will include Dr. Robert Nicholas, Ethan B. Ellis and Elizabeth Boggs. Log onto PWD MAG and select PWD ONLINE. Portions of the material posted in this area may be edited for publication.

AFTERWORD

A Commentary on Inclusion: Us and Them

Marc Mercer

It is not usual for me to write commentary for PEOPLE WITH DISABILITIES. I normally write features. On the issue of inclusive education, I feel compelled to speak to you directly and personally. There are three experiences from my life that may explain why.

"I want to say something to you. It is the whole reason I have stepped out from behind my usual role as a journalist. It is partial payment on old debts. In 1959 in California, I barely escaped becoming one of 'them.'"

Edwards AFB, California, 1959

I was placed in a class for slow learners in sixth grade in California. This was before anyone called it "special education." Thinking back, I realize that some of my classmates had developmental disabilities. I was very shy and withdrawn. Throughout my early life my family moved from place to place—my father was a professional soldier. Somehow, I lost the ability to attach to places and people and became a closed system.

I was lucky. I drew a plump, plain, middle-aged teacher named Mrs. Orr who bothered to find out what was going on with an unnaturally silent, horribly sensitive child.

She had me tested. I will always remember the day that she held me and Jimmy Butler back at lunch time.

It is amazing that I can remember her name, much less his. I have few clear memories of childhood. I could describe that sunny classroom on Edwards Air Force Base in California in startling, photographic detail. Jimmy was a slight child with glasses and a blond crewcut. He had freckles.

She spoke to him first. I don't know what she said.

I know what she said to me. She told me that she had my test results and that she was not supposed to tell me what they were. But then she did something that created a kind of magic in my life.

She reached out and touched my head and said, "But I will tell you this, Marc, you are going to Harvard."

What she did ultimately transformed my entire school career. The next year I was in an accelerated class and I never looked back.

I didn't go to Harvard, but I did get to the University of Chicago. I have never doubted that Mrs. Orr was largely responsible. In later years I several times tried to find her to thank her. I was never able to reach her.

I cannot help wondering what would have happened if the label "slow learner" had stuck.

Mobile, Alabama, 1960

A year later I attended racially segregated schools in Alabama. We lived on base. In those days, the American military was unquestionably the most integrated institution in this country. There were African-American children down the block and we played together. They were our friends.

On Monday morning, our friends got on a bus to go to a different school. I also remember what my friends from the all-white junior high school said about "niggers." They were full of hate and fear in those days just before the dawn of integration. They didn't actually know any "niggers." If they had, they couldn't have talked like that.

I found the whole thing puzzling and deeply painful.

Trenton, New Jersey, 1986

I had just started my career as a full-time freelance writer. Although I had written several important human services pieces for various organizations, I was still struggling to make a living out of a precarious business.

I got a call from Ethan Ellis. He was looking for a writer for the final report of the Governor's Task Force on Disabled Persons. That phone call was the first conversation I

ever had with a person who talked the way Ethan does.

I sometimes didn't understand him, but was scared to say so, because I didn't want to offend him. Luckily, he was very skillful in dealing with this sort of situation. Ethan can establish a warm, friendly personal contact with another human being faster than anyone I have ever met. It didn't occur to me until later to think about why and how he developed this skill.

It is fair to say that Ethan has had an impact on me that compares favorably with what Mrs. Orr did. He is today a close personal friend and an esteemed colleague.

He became a kind of intellectual mentor for me in ways that have nothing to do with disability. He is one of the two or three most able people I have met in my life.

And, do you know, I remember when two young drunks mocked him in a public bathroom in Atlantic City. I remember going to hotels and restaurants with him and seeing other people treat him in ways that make it terribly clear that they do not know that he is a human being. I have seen people in the disability community itself respond to him with what I consider inappropriate fear and anger.

I remember hundreds of small, painful encounters with thoughtless people. And I feel a familiar sense of confusion and pain. If they knew him, if they knew anyone with a disability like his, they would not act this way.

Think about it. I lived for 39 years before I got to know a person with a disability. I went to school, worked in mental health services for 10 years, traveled and conducted a varied social life. I never got to know a person who uses a wheelchair, a blind person, a deaf person, a person with cognitive difficulties or a person with cerebral palsy.

I saw them from a distance. They took the other bus. They lived in other places.

Lambertville, New Jersey, 1993

I realize that there are complex technical issues when it comes to the question of including children with disabilities in regular classrooms. I realize that inclusion needs to be a gradual and careful process. I realize that teachers need to have the support and training required to make it a success.

I do not argue against the need for specialized programs and services. I believe that there may even be a small number of individuals whom we cannot include, given current technology.

That does not excuse a failure to see this issue for what it really is. If our children grow up never meeting people with disabilities, they will continue the hate, fear and ignorance of my generation. If children with disabilities grow up exclusively in segregated environments, many will never make it back to the mainstream, will never be able to live in the community and hold meaningful jobs.

"If our children grow up never meeting people with disabilities, they will continue the hate, fear and ignorance of my generation. If children with disabilities grow up exclusively in segregated environments, many will never make it back to the mainstream, will never be able to live in the community and hold meaningful jobs."

I want to say something to you. It is the whole reason I have stepped out from behind my usual role as a journalist. It is partial payment on old debts. In 1959 in California, I barely escaped becoming one of "them." In 1960 in Alabama, I was too young and too scared to stand up for what I knew was right.

Segregation is wrong. It is wrong for "us" and it is wrong for "them." ❑

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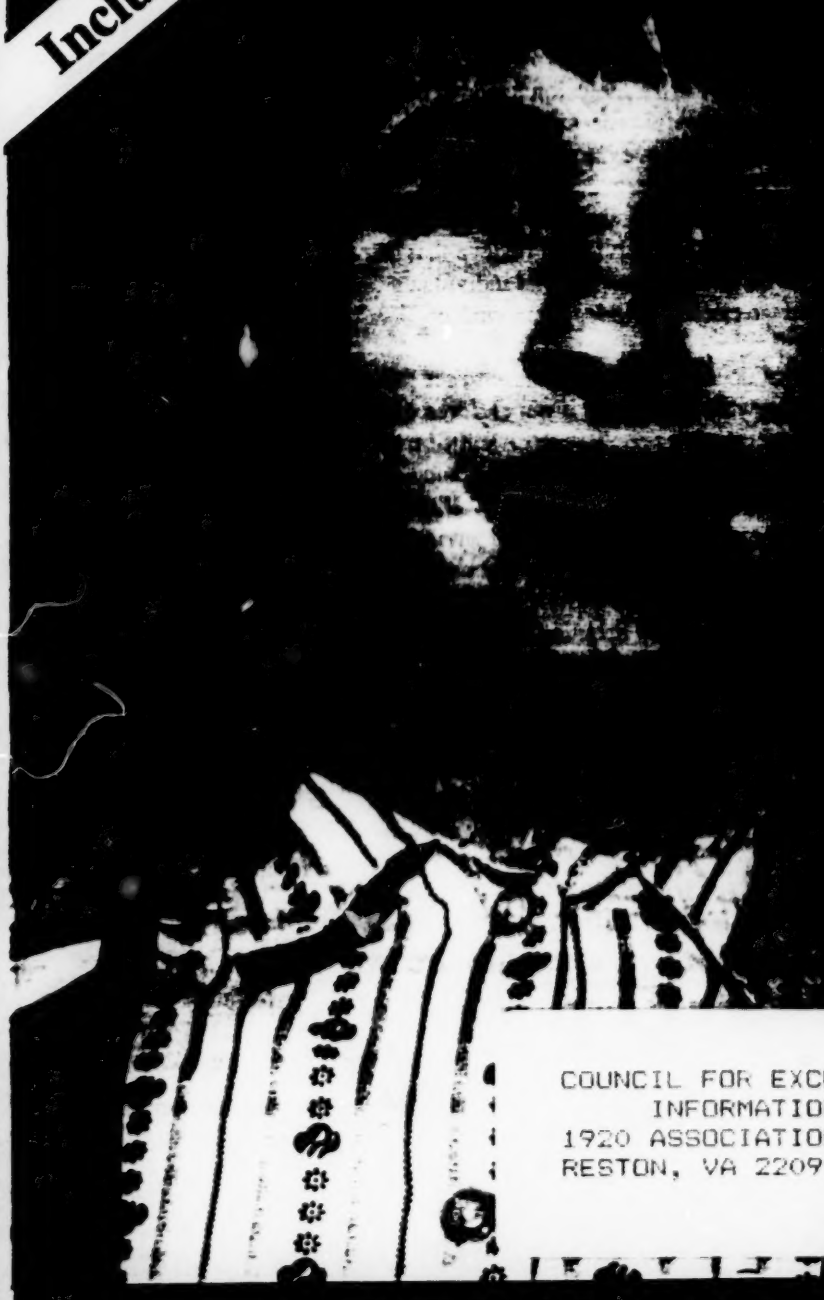

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